

Introduction

National Patient Advocate Foundation (NPAF) represents patient and caregiver voices, both the powerful stories of individuals and the collective needs of the community. Since 1996, we have been dedicated to expanding equitable access to affordable quality care, particularly for our nation's most vulnerable populations. NPAF is the advocacy affiliate of Patient Advocate Foundation (PAF), which provides direct assistance and support services for primarily low-income families confronting complex, chronic and serious illness to help reduce distressing financial and other burdens they may experience because of their conditions.

NPAF develops and drives evidence-based solutions related to access, affordability and quality at federal, state and local levels that advance person-centered policies and practices in four key areas: skilled communication, shared decision-making, quality care improvement and safety net services navigation. The goal is a system that matches treatments and services with patient and family values. Experiences reported from the thousands of people served annually through PAF's efforts and input from patients and caregivers about what they need and value throughout the care continuum fuels our person-centered and family-focused agenda.

Through targeted research, advocacy engagement, and stakeholder partnerships, NPAF uses its thought leadership and resources, supported by patient data collected, to influence public policies and practices that put people at the heart of healthcare.

Policy Principles Document

This document is updated and board-approved annually, serving as NPAF's menu of policy recommendations supporting its mission to achieve equitable access to affordable quality care. It includes a principles overview and detailed background brief providing relevant references corresponding to each set of the principles. NPAF staff use these principles to guide specific positions and priorities for legislative, regulatory and other influential public policy engagement that will advance the organization's person-centered care agenda nationwide.

Equitable Access Principles

NPAF focuses on policies that promote equitable access to insurance coverage and quality care under the Affordable Care Act, Medicare, Medicaid and other public and commercial plans, particularly to support needs of low-income and other disadvantaged populations confronting complex, chronic or serious illnesses, aligned with the following principles:

1. Coverage Protections and Essential Health Benefits

- a. Understandable educational resources and information about health insurance coverage, accessibility and beneficiary responsibility should be readily available to the public.
- b. All health plans should be held accountable for providing:
 - Adequate coverage of essential health benefits;
 - Clear and understandable appeals processes;
 - Transparent provider networks and formularies;

- Consistent coverage that does not make plan changes after open enrollment ends; and
 - Quality evaluation and reporting about insurance plans available in the market;
- c. Key provisions that protect patients from discriminatory practices and outcomes should be expanded or at least preserved among all health insurance plans and review activities, including opposition to any policies that:
- Remove pre-existing conditions restrictions;
 - Impose continuous coverage requirements and penalties;
 - Impede individual choices among plans;
 - Significantly increase premium and out of pocket costs;
 - Restrict coverage and impose lifetime limits;
 - Destabilize the insurance market; or
 - Undermine federal cost-sharing reduction payments that lower out-of-pocket costs (deductibles, coinsurance and copayments) for qualifying, lower-income enrollees.

2. Medicaid and Children’s Health Insurance Program (CHIP)

- a. Medicaid and CHIP coverage should be sustained and expanded to meet the needs of low income adults and children, particularly families confronting complex, chronic or serious illness.
- b. Limitations on Medicaid eligibility, coverage and benefits that impede equitable access to care must be avoided, including burdensome cost-sharing and work requirements for beneficiaries.

3. Insurance Benefit Design and Utilization Management

- a. Health plans should be accountable for:
- Implementing clear, understandable, flexible and evidence-based benefit design and utilization management practices;
 - Completing utilization management determinations within 24 hours for urgent medical needs, and within 48 to 72 hours for all other medical needs; and
 - Transparent utilization management implementation processes that inform patients and practitioners about plan updates that may result in changes to prescribed treatments.
- b. Step therapy protocols and other utilization management practices should not impede on professional clinical judgement or diminish the patient-provider relationship and their shared decision-making.

4. Network Adequacy

- a. Insurers should provide understandable information for potential enrollees explaining network design, numbers and types of providers and their geographic distribution to promote meaningful individual choice among plans, practitioners and networks.
- b. Networks should be evaluated and adjusted as needed to expand reach of community providers and equitable access to care supporting needs of vulnerable populations across all insurance markets.

- c. Health plans should maintain accurate and up-to-date network provider directories for the public that are accessible and understandable.

5. Clinical Trials

- a. Promoting equitable and affordable access to clinical trials for all populations is an essential aspect of quality care delivery, and trials participation expansion efforts should include:
 - Streamlined implementation and enrollment processes;
 - Collaborative development and dissemination of culturally appropriate information about clinical trials and enrollment opportunities to reach diverse patient populations;
 - Coverage of routine health costs and support for non-medical costs associated with trial participation (e.g., transportation costs);
 - Increasing access to and participation from currently underrepresented groups; and
 - Implementation of and improvement in expanded access provisions that follow established ethical guidelines enabling therapeutic availability for individuals unable to participate in a clinical trial and who have exhausted other treatment options.

6. Personalized Care and Precision Medicine

- a. Access to personalized care, diagnostics and precision medicine should be equitably available to foster shared decision-making and value-based care that prioritizes patient and family preferences while also improving clinical outcomes.
- b. Adequate funding for medical and health services research and innovation should be available, with emphasis on advancing innovations in development and delivery of person-centered care.

Affordable Care Principles

High costs of care often force families to choose between the burdens of paying for treatments and meeting living expenses. To minimize financial distress, household material hardships and related social determinants of health that disproportionately affect vulnerable populations, NPAF prioritizes policies that contain total costs of care and improve healthcare affordability aligned with the following principles:

1. Safety Net Supports and Services

- a. All patients should be screened to assess their financial and social support needs, transportation and household material hardships concerns (i.e., food, energy, housing security) and safety net services eligibility throughout the continuum of care, with processes in place providing timely referral to appropriate programs.
- b. Medicaid and CHIP coverage and services provided through federally qualified health centers and other programs supporting care needs of vulnerable populations should be sustained, strengthened and expanded.
- c. Research supporting development and dissemination of effective interventions that link vulnerable populations with needed safety net supports and services should be prioritized.

2. Total Costs of Care and Pricing

- a. Understandable and transparent cost information and reliable resources should be publicly available to support consideration of treatment benefits and tradeoffs in the context of person-centered care planning and shared decision-making throughout the care continuum and across all care settings.
- b. Patients should have opportunities to learn about and meaningfully discuss the cost of their care, both before and after making a treatment decision, in ways that are culturally appropriate and sensitive to the needs and circumstances of patients and their families.
- c. Pricing transparency regulations should be applicable to all sources of patient cost and all stakeholders who participate in the creation of such costs to give patients access to information that helps them make more informed choices and prepare for the financial obligations associated with their care.
- d. Approaches that foster market competition that can lead to lower prices and cost-sharing should be implemented.
- e. Equitable pricing between oral and intravenous treatments and limitations on cost-sharing requirements for essential health services including cost difference between benefit tiers should be ensured.
- f. Savings generated through discount programs or price negotiations need to benefit patients, particularly vulnerable and low-income patients.

3. Medical Debt and Balance Billing

- a. Patients should have sufficient protections and time to either contest or reconcile medical debts with providers or payers.
- b. Equitable credit rating and fair reporting practices should be prioritized to minimize distressing medical debt burdens that can follow patients and families for years, even after the debt has been settled.
- a. Patients should be notified when they use out-of-network providers or services and should not be held financially responsible for balance billing due to unexpected out-of-network care.

Quality Care Principles

Patients must be able to participate as partners in their care decisions in ways that shape a coordinated care experience and match treatments with personal values. In the context of implementing key aspects of the Medicare Access and CHIP Reauthorization Act (MACRA) of 2015 and MACRA's subsequent regulatory provisions, multiple value-based initiatives are underway using payment models that introduce shared risk and link provider payments to outcomes. NPAF prioritizes integration of person-centered care principles throughout the care continuum and in all aspects of these value-based reforms, aligned with the following principles:

1. Value-Based Care and Health System Reform

- a. Patients and families should be positioned as essential stakeholders for contributing person-centered quality care perspectives and expertise in alternative payment models,

value assessments, clinical pathways, quality measures, and various other health reform initiatives.

- b. Transparent processes should be outlined throughout development, implementation, and evaluation of new payment and care models that consistently include patient and family perspectives about the quality and value considerations that are important to them.
- c. Value-based care and payment models should include quality measures and patient reported outcomes that evaluate availability of person-centered communication, shared decision-making, care coordination and essential support services that match treatments with values.
- d. Person-centered models of care should be prioritized to deliver better quality care and value in ways defined in collaboration with patients and families and grounded on what is important to them.

2. Shared Decision Making and Patient Engagement

- a. Patients and families should be provided with resources and decision support tools that foster communication with their care team about their personal values and preferences, shared decision-making and goal concordant care planning.
- b. Communication skills development through evidence-based training should be prioritized for all health professionals to improve shared decision-making and person-centered quality care that matches treatment with values.
- c. Processes and tools that determine treatment options such as clinical pathways and value assessments should be disclosed and improved in ways that allow for integration of personalized patient characteristics so that patients can make informed decisions that reflect what matters to them in partnership with their care team.
- d. Patient- and caregiver- reported outcomes should be incorporated into quality improvement initiatives, value assessments and care models.
- e. Opportunities for patient and caregiver engagement in research, regulation, evaluation, quality improvement initiatives, alternative payment models, measurement, and advisory boards, councils and committees should be expanded to prioritize integration of person-centered perspectives and care principles in these activities.
- f. Transparency and disclosure about the development and use of protocols that influence or determine treatment options and decisions should be improved to ensure person-centered implementation that preserves the patient-provider relationship, shared decision-making and personalized centered care.

3. Palliative Care Integration

- a. Improving awareness for the public and professionals about palliative care as an established model for delivering person-centered care that maximizes quality of life throughout the continuum of serious and complex chronic illness should be prioritized.
- b. Equitable access to palliative care services and professional workforce skills training in generalist palliative care core competencies including skilled communication, care coordination, and symptom management should be enhanced and expanded in all care settings.

- c. Research support should be prioritized to build the palliative care evidence base for improved quality care delivery throughout the continuum of care.
- d. New person-centered quality measures and standards should be developed that emphasize skilled communication to help match treatments with patient and family values, preferences and needs.

4. Pain Management

- a. Policies addressing the opioid epidemic should be balanced to preserve equitable access to pharmacologic and non-pharmacologic therapies for people with pain.
- b. Research investment for development of new pain management interventions should be prioritized.
- c. Training, education and resources availability for public and professionals addressing risk assessment and management of substance abuse outcomes during opioid treatment, safe prescribing and use, storage and disposal of prescription pain medications should be prioritized.

5. Family Caregivers Support

- a. Family caregivers should be identified and routinely assessed for their caregiving information and support needs as part of the unit of care.
- b. Equipping family caregivers with the information, training and resources they need to support them in their caregiving roles and responsibilities should be prioritized and systematized.
- c. Research investment supporting the development and implementation of effective interventions for family caregivers should be prioritized.